

Data collection obligations of syringe distribution programs v1.2

There are 37 questions in this survey.

You are being invited to participate in a research study titled ‘Data collection obligations of syringe distribution programs’. This study is being done by Peter Davidson Ph.D. from the University of California - San Diego (UCSD). You were asked to participate in this study because you work or volunteer at a syringe distribution program.

The purpose of this research study is to find out how common it is for syringe distribution programs to be required to collect data from people receiving syringes by funders or local government, and to find out how data collected from people receiving syringes from syringe distribution programs gets used. If you agree to take part in this study, you will be asked to complete an online survey/questionnaire. This survey/questionnaire will ask questions about the syringe distribution program you work at, including what (if any) types of data you collect, whether you’re collecting data because your program is required to in order to receive funding or authorization to operate, and how any data you collect gets used by either your program or by anyone else. The survey will take about 10 minutes to complete.

There may or may not be any direct benefit to you or your program from this research. The investigator, however, may learn more about how common it is for syringe distribution programs to be required to collect data and how or whether that data gets used.

There are minimal risks associated with this research study. The primary risk would be the potential for loss of confidentiality if we were to fail to keep data from this study securely. To minimize this risk, we do not ask your name or the name of your organization. All your responses to this survey are stored encrypted, and any papers or reports we write using survey responses will only use summary data. At the very end of the survey we ask if you’d like to be contacted in the future if we have a followup study, and if you agree we record your contact information separately from the survey so they can never be linked. All research records from

this study will be kept confidential to the extent allowed by law and may be reviewed by the UCSD Institutional Review Board.

Your participation in this study is completely voluntary and you can withdraw at any time by simply exiting the survey. You can also skip any question you prefer not to answer. Choosing not to participate or withdrawing will result in no penalty or loss of benefits to which you are entitled.

If you have questions about this project or if you have a research-related problem, you may contact the researcher, Peter Davidson, at (415) 271-9474 or by email at pdavidson@ucsd.edu. If you have any questions concerning your rights as a research subject, you may contact the UCSD Human Research Protections Program Office at 858-246-HRPP (858-246-4777).

By clicking “You agree” below you are indicating that you are at least 18 years old, have read this consent form, and agree to participate in this research study. Please print a copy of this page for your records. *

Choose one of the following answers

Please choose **only one** of the following:

- I agree
- I do not agree

How long has your program been distributing syringes to people who use drugs

Choose one of the following answers

Please choose **only one** of the following:

- Less than one year
- 1 to 5 years
- 6-10 years
- More than 10 years

Is your program part of a larger organization that serves people other than people

who use drugs, or is it a 'stand alone' program that almost entirely serves people who use drugs

Please choose **only one** of the following:

- Stand alone program
- Part of a larger organization

What gender does the person in charge of syringe distribution services identify as? (This question is being asked because Sue Purchase (and others) wanted to know how many programs in the US are run by women. As a reminder, all questions are completely optional)

Please choose **only one** of the following:

- Female
- Male
- Other

What state is your program located in?

Please choose **only one** of the following:

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
-

Connecticut

- Delaware
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania

- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- District of Columbia
- American Samoa
- Guam
- Northern Mariana Islands
- Puerto Rico
- United States Minor Outlying Islands
- Virgin Islands, U.S.

What is your role in your organization?

Please choose **only one** of the following:

- I'm the executive director or equivalent
- I'm in charge of our syringe distribution program but not of the organization as a whole
- I'm not in charge of the syringe distribution program as a whole, but I have another leadership role
- I don't have a leadership role, but I work or volunteer for the syringe distribution program
- Other

How long have you worked for or volunteered at your organization (in any role)?

Please choose **only one** of the following:

- Less than one year
- 1 to 5 years
- 6-10 years
- More than 10 years

What is your program's main source of funding (if you're part of a larger organization, where does most of the money for the syringe program come from)

Please choose **only one** of the following:

- State government
- County or City government
- Foundations
- Donations
- Other

Do you currently collect any data directly from people receiving syringes by asking them questions?

Please choose **only one** of the following:

- Yes
- No

Have you ever done this even if you don't now?

Please choose **only one** of the following:

- Yes
- No

Do you currently collect any data about people receiving syringes other than by asking them directly (eg by counting people, or recording things like their gender or the number of syringes you gave them)

Please choose **only one** of the following:

- Yes
- No

Has your organization ever collected this type of data that you know of, even if you don't any more?

Please choose **only one** of the following:

- Yes
- No

Is your organization currently required to collect *any* information from or about service users by a funder as a condition of receiving funding?

Please choose **only one** of the following:

- Yes
- No

In the past has any funder required you to collect information from or about service

users that you know of?

Please choose **only one** of the following:

- Yes
- No

Is your organization currently required to collect any information from or about service users by any state or local government organization as a condition of being able to operate legally?

Please choose **only one** of the following:

- Yes
- No

In the past has any government organization required you to collect information from or about service users that you know of?

Please choose **only one** of the following:

- Yes
- No

What kinds of information are you currently collecting from or about the people who use your service?

Please choose **all** that apply:

- Basic demographics, such as age, gender, ethnicity
- Personally identifying information, such as names or dates of birth
-

A non-identifying unique identifier, such as a membership number or letters from their name or date of birth

- Number of syringes given out and/or brought in
- Other services you provided to that person, such as naloxone, other medical or social services, or referrals to other services
- Information about behaviors, such as how often someone is injecting drugs, or what drugs they're using or whether they've overdosed recently or been in drug treatment recently
- Information about other parts of peoples lives, such as whether they've been arrested recently, or used a ER recently
- Information about whether the person has been in drug treatment recently
- Other:

Does your own agency use any of this information for any reason other than reporting it to outside agencies?

Please choose **only one** of the following:

- Yes
- No

How do you make use of this data?

Please choose **all** that apply:

- To help with ordering supplies
- To help improve services
- To help write new grant applications (not reporting to existing funders)
- Other:

How often does your program review this data for any of these purposes?

Please choose **only one** of the following:

- Weekly
- Monthly
- Quarterly
- Annually
- Less often than annually

Does any funder who requires you to report data to them ever tell you what they do with the data?

Please choose **only one** of the following:

- Yes
- No

What have they told you they use the data for?

Please write your answer here:

Do they ever report anything back to you which comes from the data you give to them?

Please choose **only one** of the following:

- Yes
- No

What kind of information do they report back to you?

Please write your answer here:

Does any governmental organization who requires you to report data to them ever tell you what they do with the data?

Please choose **only one** of the following:

- Yes
- No

What have they told you they use the data for?

Please write your answer here:

Do they ever report anything back to you which comes from the data you give to them, like program feedback or any kind of data or analysis which would help your program?

Please choose **only one** of the following:

- Yes
- No

What type of feedback or report do they give you?

Please write your answer here:

Roughly how many minutes would you say that it takes to collect data from or about each person receiving syringes (eg asking people questions or filling in forms)?

Only numbers may be entered in this field.

Please write your answer here:

-

And on average about how many people do you give syringes to each week?

Only numbers may be entered in this field.

Please write your answer here:

-

Or to put it another way, how many times did you collect data about handing someone syringes in the last week?

How many hours a week would you say gets spent doing other data related activities, such as data entering paper forms into electronic systems, or preparing data for funders or government agencies.

Only numbers may be entered in this field.

Please write your answer here:

-

Has the need to collect data ever affected who you could have as a volunteer or staff member (eg you have to make sure all volunteers have a basic level of literacy so they can fill in data forms)

Please choose **only one** of the following:

- Yes
- No

Can you say more about this?

Please write your answer here:

Have you ever had any concerns that your need to collect data from service users might stop some people from using your service (eg people who have mental health issues or concerns about law enforcement being scared off)?

Please choose **only one** of the following:

- Yes
- No

Can you say what your concerns have been?

Please write your answer here:

Is there anything else you'd like to tell us about how the need to collect data impacts your organization's ability to distribute syringes, or comments you'd like to make about the questions you just answered?

Please write your answer here:

Thank you for taking the time to consider participation.

Thank you for completing this survey. We hope to do a larger study of these issues in the future. If you would be willing to be contacted in the future to ask if you wanted to participate in any new study, click the link below. This will take you to a separate website for you to enter your contact info (so your contact info is not connected to the survey you just completed in any way). Otherwise, you're done. Thanks again.

[Link to optional contact information screen here]

Submit your survey.

Thank you for completing this survey.